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Authors

Shrestha, Isha

Ming, Kristin

Jimenez, Veronica

et al.

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Title:

Lessons learned from an HIV pre-exposure prophylaxis coordination program in San Francisco primary care clinics

Authors:

Isha Shrestha^{1,3}; Kristin Ming^{1,3}; Veronica Jimenez¹; James Wendelborn¹; Alexander Vazquez¹; Wayne Steward, PhD¹; Hyman Scott, MD, MPH²; Parya Saberi, PharmD, MAS¹

1 Department of Medicine; University of California, San Francisco; San Francisco, CA

2 Bridge HIV; San Francisco Department of Public Health; San Francisco, CA

3 These authors contributed equally to this work

Corresponding Author:

Parya Saberi, PharmD, MAS

UCSF Box 0886

550 16th St., 3rd floor

San Francisco, CA 94143

Telephone number: (415) 476-6357

FAX number: (415) 476-5348

E-mail address: parya.saberi@ucsf.edu

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Abstract

HIV pre-exposure prophylaxis (PrEP) has shown high efficacy and effectiveness for HIV prevention; however, many individuals with PrEP indications are not receiving PrEP. PrEP Coordinators work closely with patients and healthcare providers to increase PrEP access, and they provide unique insights into the inner workings of PrEP care and service delivery. Here, we discuss key challenges and recommendations for improved PrEP service delivery (including training PrEP Coordinators to manage PrEP panels, making PrEP a part of routine care and optimizing EHRs, designating a PrEP “champion” who can strengthen communication and leadership, using a proactive approach to increase PrEP retention, and training providers and PrEP Coordinators to meet youth-specific needs) from our discussions with the PrEP Coordinators who led PrEP panel management in San Francisco Department of Public Health primary care clinics.

Background

HIV pre-exposure prophylaxis (PrEP) has shown high efficacy and effectiveness for HIV prevention.¹ However, only 18.1% of the nearly 1.2 million individuals with a PrEP indication have received a PrEP prescription.² Panel management strategies (population-based approaches that focus on addressing the unmet health needs of patients)^{3,4} implemented by PrEP Navigators or Coordinators have been associated with patients being referred to a provider and prescribed PrEP;⁵ earlier PrEP initiation;³ and assisting with patient education and resolution of insurance and pharmacy barriers.^{6,7} Few studies have examined the use of non-medically trained PrEP Coordinators,⁸ and none have examined their perspectives regarding challenges and recommendations for PrEP delivery. Although the terms PrEP Navigator and PrEP Coordinator have not been fully defined, a PrEP Navigator's role focuses on insurance navigation and linkage to a provider.⁶ A PrEP Coordinator's role is consistent with task sharing principles in providing a spectrum of services, including PrEP outreach, evaluating HIV risk, ordering and monitoring labs, and completing quarterly follow-ups.⁹ PrEP Coordinators manage the majority of PrEP services in collaboration with the provider.⁶

Between 2018–2020, we implemented the PrEP Optimization Intervention (PrEP-OI) study including two components to support providers with PrEP uptake and management: 1) PrEP coordination overseen by four non-medically trained PrEP Coordinators at 12 San Francisco Department of Public Health (SFDPH) primary care clinics; and 2) a web-based panel management tool called PrEP-Rx used by the PrEP Coordinators.^{9,10} Upon completion of the PrEP-OI study, the research team met with the PrEP Coordinators to discuss their perspectives. Here, we share their insights on challenges and recommendations for improving PrEP services.

Challenge 1: Lack of personnel responsible for managing PrEP care.

Evidence suggests that primary care providers are less aware of PrEP and willing to prescribe versus infectious disease and HIV specialists.^{8,11} However, HIV specialists tend to work in contexts where patients are already living with HIV. This “purview paradox” results in a shortage of clinicians responsible for managing PrEP care.^{8,11} Additionally, many providers have noted lack of time, lack of PrEP knowledge, pharmacy and insurance issues,

and lack of methods to contact patients unresponsive to telephone calls as barriers for PrEP initiation and follow-up.⁶

Recommendation 1: Train PrEP Coordinators to manage PrEP panels.

Introducing PrEP Coordinators in the primary care setting can increase PrEP uptake, persistence, and management. As part of PrEP-OI, PrEP Coordinators were trained to conduct activities along the PrEP care continuum, including conducting PrEP and post-exposure prophylaxis (PEP) counseling, evaluating HIV acquisition risk, educating patients on sexually transmitted infection (STI) self-swabbing, ordering PrEP initiation and continuation labs (using SFDPH standing order protocols and following Centers for Disease Control and Prevention (CDC) guidelines)¹², navigating insurance and coverage (including patient assistance programs for uninsured and underinsured patients and switching patients from brand name to generic PrEP medications), “pending” PrEP prescriptions for providers, notifying providers on patients experiencing side effects, and educating patients on new PrEP medications or dosing strategies.⁶ Training took up to 48 hours and included reading, didactics, shadowing, role-playing, and ongoing weekly supervision and case discussion.⁹ Providers noted increased capacity, capability, and desire to offer PrEP and manage patients on PrEP after a PrEP Coordinator was assigned to their clinic.⁶ Having PrEP Coordinators decreased barriers via faster resolution of insurance and pharmacy issues, providing patient education and building trust, and removing the need for quarterly provider appointments or external referrals for PrEP initiation.⁶ In addition, training PrEP Coordinators for provision of phlebotomy services can further improve timely lab scheduling and follow-up.

Challenge 2: PrEP is not a part of routine care in primary care clinics.

The quantity and complexity of primary care tasks create competing priorities in primary care settings which often means that providers are not offering PrEP, leading to fewer patients receiving it. However, integrating PrEP into routine primary care could scale up PrEP use and help reach populations with low PrEP uptake, such as cis-gender women and youth.¹¹

Recommendation 2: Make PrEP part of routine care and optimize use of EHRs.

We suggest offering PrEP education to all patients and prescribing for anyone who is interested and medically eligible, regardless of disclosed HIV risk. This can be achieved by standardizing PrEP screening at new patient, yearly follow-up, and sexual/reproductive health visits using a destigmatizing question such as, *“We are telling all of our patients about a pill that can prevent HIV, are you interested in learning more about it?”* Focusing on education rather than risk assessment can help reach patients who are not aware of PrEP and/or may not feel comfortable disclosing their risk behaviors.¹³ Framing PrEP as a tool to reduce anxiety about contracting HIV, enhance intimacy, and care for one’s health¹⁴ encourages shared decision-making.

The PrEP screening question can be inserted into EHR templates used by providers and staff. Any healthcare team member can offer PrEP education and refer patients to the PrEP Coordinator for further counseling and PrEP initiation. Standing labs and/or PrEP order sets can also help providers and PrEP Coordinators efficiently order PrEP labs.

Clinics can standardize identifying PrEP candidates by generating STI registries of patients who test positive for STIs or have frequent screening. An example used within SFDPH included patients not living with HIV who tested for HIV more than two times within a 24-month period, had a positive syphilis rapid plasma reagin, were screened for rectal STIs, or were diagnosed with gonorrhea or chlamydia in the last 12 months. Similarly, patients on PEP in the past may be appropriate PrEP candidates. Once identified, PrEP Coordinators or other clinic personnel can reach out to patients and offer PrEP.

Challenge 3: Inconsistent PrEP support and buy-in from clinic leadership.

When a PrEP program is new, there can be difficulties engaging leadership to see PrEP as a priority, leading to less trust in the program from providers and missed opportunities for PrEP referrals. Examples include a lack of leadership around: 1) developing changes to workflows, e.g. universally offering PrEP to all patients; 2) engaging providers and staff in referring patients, e.g. during STI treatment visits; 3) engaging in problem-solving around barriers, e.g. lack of lab hours or personnel; and 4) ensuring PrEP Coordinators are integrated into clinics, e.g. by providing workspace or including them in appropriate meetings.

Recommendation 3: Designate a clinical PrEP “champion” who can strengthen communication and leadership.

It is crucial to have engaged leadership for creating a clinical culture of prioritizing sexual health and HIV prevention. To accomplish this, it can be helpful to identify a clinical PrEP “champion” at each clinic. This provider would work closely with leadership and PrEP Coordinators to streamline workflows, serve as an additional PrEP resource, and serve as a reminder to the clinic to prioritize sexual health and HIV prevention. We found the presence of a designated PrEP champion at the PrEP-OI clinics influential by meeting weekly with the PrEP Coordinator to discuss progress and barriers, introducing the PrEP Coordinator to providers and staff, inviting the PrEP Coordinator to HIV quality improvement meetings, providing PrEP clinical updates, serving as a PrEP resource, and ensuring that providers knew where to direct PrEP-related questions.

Challenge 4: Difficultly retaining patients on PrEP.

Retaining patients in PrEP care can present a challenge due to limited clinical support. PrEP-OI providers revealed that they had a more “reactive” follow-up strategy, meaning that they relied on the patient to contact the clinic for PrEP-related needs such as requesting refills and ordering labs.⁶ As a result, patients who would not contact the clinic had low PrEP persistence. Additionally, some patients would not start PrEP due to insurance issues, or would discontinue and later restart PrEP without completing PrEP labs. Providers also reported barriers such as difficulty reaching patients unresponsive to telephone follow-ups and patients experiencing homelessness, substance use disorders, or mental health challenges.⁶

Recommendation 4: Use a proactive and diversified approach to increase PrEP retention.

A proactive approach to PrEP retention can include a call or text the day after prescribing to confirm patients have picked up and started PrEP. In PrEP-OI, providers noted that having PrEP Coordinators familiar with patient assistance programs and insurance coverage resulted in reduced time from PrEP prescription to initiation and improved retention.⁶ Additionally, the PrEP Coordinators followed up with patients one week and one month after PrEP initiation to assess side effects and adherence. In PrEP-OI, close follow-up around PrEP initiation resulted in higher patient retention.

Another proactive approach is expanding communication methods such as messaging through the EHR patient portal, email, telephone calls, and text messaging. Having direct access to a PrEP Coordinator also resulted in increased rapport with patients who were discouraged by long wait times when calling the clinic to schedule lab appointments or contacting the pharmacy for refills.

Expanding PrEP outreach beyond the physical clinic location, meeting patients where they may be residing (e.g., at shelters), and forming relationships with community liaisons can increase engagement with patients experiencing psychosocial barriers, substance use disorders, and homelessness. We also suggest having PrEP Coordinators speak the language that the patient is most comfortable with and translating education materials (see PrEP-OI's English, Spanish, and Chinese resources at prep.ucsf.edu). Having language concordance can result in fewer miscommunications, patients reporting feeling more comfortable speaking about personal matters, higher patient satisfaction, and enhanced PrEP self-efficacy.⁶ Finally, we recommend partnering with local community-based organizations to create PrEP materials that represent the patient population and are inclusive, community-informed, and highly visible at clinics (e.g., askaboutprep.org).

Challenge 5: Adolescents and Young Adults (AYAs) face additional barriers in accessing PrEP.

Some AYAs may feel reluctant to discuss gender identity and/or sexual orientation with providers,¹⁵ especially as they may still be exploring their identities. Lack of confidentiality may decrease AYAs seeking sexual health services and AYAs who rely on their parent's/guardian's insurance are less likely to take PrEP.^{13,16} Furthermore, some AYAs initiating PrEP are learning to navigate complex healthcare systems for the first time independently. They may not know who to contact if their prescription is not covered or denied at the pharmacy and leave the pharmacy without their medication, leading to delayed PrEP initiation or gaps in use.

Recommendation 5: Train providers and PrEP Coordinators to address AYA-specific needs.

Training providers and PrEP Coordinators to use inclusive language¹⁵ and address youth-specific confidentiality concerns can help AYAs feel more comfortable discussing sexual health. In SFDPH, a Youth Emergency Fund was created to help AYAs access PrEP who

were uninsured or did not want to use their parent's/guardian's insurance. AYAs were also able to pick up PrEP at their primary care clinic to minimize confidentiality concerns related to going to a pharmacy.

It may be beneficial for AYAs to access PrEP care through their school-based health centers.¹⁷ Furthermore, some AYAs may prefer to use pharmacies that offer text messaging. Finally, providing education on the steps to refill and pick up a prescription, as well as providing consistent follow-up may be especially helpful for AYAs who are learning to engage and build trust with healthcare systems.

Conclusion

We discussed key challenges and recommendations from the PrEP Coordinators' perspective that emerged from their experiences implementing the PrEP-OI study in SFPDPH primary care clinics. Our recommendations include training PrEP Coordinators to manage PrEP panels, making PrEP a part of routine care and optimizing EHRs, designating a PrEP "champion" who can strengthen communication and leadership, using a proactive approach to increase PrEP retention, and training providers and PrEP Coordinators to meet AYA-specific needs. We believe that addressing these challenges, most of which can be resolved by support from clinic leadership for PrEP programs and PrEP Coordinator training, can enhance PrEP services and patient satisfaction.

Panel management approaches have been used to deliver PrEP care in specialty PrEP programs and in STI clinics.^{18–20} Primary care providers have reported that PrEP Coordinators can increase their efficiency and capacity to manage patients on PrEP.⁶ Even though medically trained personnel can play the PrEP Coordinator role, the PrEP-OI study successfully trained non-medical personnel to take on this role. At this time, there are limited publications related to PrEP coordination being conducted by non-medical personnel. However, similar care coordination approaches have been successfully used in other primary care settings.²¹

Given that PrEP Coordinators work closely with patients and providers, they offer unique insights into the challenges and improvement recommendations of PrEP service delivery.

Future studies collecting patient perspective data will be needed to further improve the quality of clinical PrEP services.

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